

# Canada's Hepatitis C News Bulletin

www.hepcbc.ca

# WORLD HEPATITIS DAY 2015 VANCOUVER

Photos from World Hepatitis Day, Vancouver July 28, 2015, held at Creekside Community Centre, near False Creek.



ANDREW OLDHAM, general mgr. and producer of Rolling Stones from 1963-1967, spoke of many in entertainment industry with

hepatitis C – rolling out the Generation Hep Dot Com "Baby Boomer hep C testing" campaign. See: http://www.generationhep.com!



WHD VANCOUVER 2015 PLANNING COMMITTEE: Sandi Mitchell of BCCDC, Andrew Oldham – Mgr. of Rolling Stones 1963-67, Rosemary Plummer of HepCBC, Alan Huang-independent volunteer, Tatiana Pakhomova of Purpose Society, Denise Thomas of First Nations Health Authority, Shakuntala Soden of HepCBC, and Deb Schmitz of Pacific Hepatitis C Network.



Shawn Sharma, General Mgr. of Vancouver Infectious Diseases Centre, with portable Fibroscan machine at WHD.

### HOLKIRA PAK<sup>TM</sup> APPROVED!

On World Hepatitis Day 2015, the BC government announced BC PharmaCare would now cover another new interferon-free hepatitis C treatment, AbbVie's Holkira Pak<sup>TM</sup>. It is also covered in Ontario, Quebec, Yukon, Manitoba, Saskatchewan, and Nova Scotia - perhaps others by the time this is published! This welcome news means that people in BC with genotype 1 now have another choice for treatment which has excellent results for people with or without cirrhosis. It also means that there is now some competition for Gilead's market, which we hope will help control the high cost of new hepatitis C treatments. This treatment (paritaprevir + ritonavir + ombitasvir + dasabuvir) also includes ribavirin in all cases except for people with genotype 1b with no cirrhosis. However, the treatment time for Holkira Pak<sup>TM</sup> (12

(Continued on page 3)

#### **MERGER**

Janssen announced that it has entered into an exclusive worldwide license and collaboration arrangement with Achillion Pharmaceuticals, Inc., to develop and, upon regulatory approval, commercialize one or more of Achillion's lead hepatitis C virus (HCV) assets which include ACH-3102, ACH-3422 and sovaprevir.

#### **INSIDE THIS ISSUE**

WHD / Holkira Pak<sup>TM</sup> Approved!

Merger / Allen McCulloch

Daklinza<sup>TM</sup> News/More Leaders Tested

Conferences / Marathon

Honour Roll

**Compensation News** 

Care Programs / Compensation

Coming Up

# LOSS OF HEPCBC BOARD MEMBER

# ALLEN MCCULLOCH



September 17, 1953 - July 11, 2015

On Saturday July 11, 2015, our beloved Allen passed away at home in Mill Bay, B.C., with his family by his side. Born in Vancouver, B.C., September 17, 1953. Allen was a loving, devoted family man and a loyal friend with a big heart, he had beautiful eyes, a warm smile and an infectious, hearty laugh. Passionate always, living his life to the fullest. Always game for any adventure, loved people and was happiest when he was out in nature or "making things happen", volunteering, cooking, entertaining, sports, firefighting, working and public service. His extensive travels around the world brought him many, cherished lifelong friends and helped develop his vast knowledge of the world he loved. Predeceased by his loving mother Alma, father Glen, and his sister Valerie. Sadly missed, fondly remembered and will be loved forever by his partner Susan Malloch and her large clan, including 7 grandchildren, his two daughters Jenn and Sarah and their mother Diane, his sister Anne Klein (Steve), niece Kelly Little (Mike), nephew Patrick Scott (Jenn), 5 great nieces and 1 great nephew, and his 5 loyal canine

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#### ORDER OR DONATION FORM

NOTE: Ordering (or donating) via Credit Card or PayPal is available online at

www.hepcbc.ca/hepcbc-order-form/ OR...

Fill out form below with a cheque made out to "HepCBC" - Send to our NEW address:

> HepCBC #20-1139 Yates Street Victoria, BC V8V 3N2

Name:	
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☐Membership with voting privileges...FREE\*

■ Bulletin through mail, Subscribe 1 year. \$10.00

□ Peppermint Patti's FAQs through mail...\$20.00

□ Donation enclosed.....\$

(You will receive an annual charitable tax receipt)

TOTAL ENCLOSED.....\$

\*Only name and email address required for emailed bulletin.

Membership also requires a postal address.

We will mail you a member package with pamphlets, yellow and red ribbon pins, information about volunteering opportunities, and how to participate in our annual general meeting, plus other ways to make your voice heard.

(Note: Nothing mailed to you from HepCBC will have ANY reference to hepatitis on the envelope.)

Registered Canadian charitable organization since 2001. No. 86800-4979-RR00001.

\*\*Download the *hepc.bull* free (since 2001) at www.hepcbc.ca/hepc-bull-monthly-newsletter/

SUBMISSIONS: The deadline for any contributions to the hepc.bull<sup>©</sup> is the 15<sup>th</sup> of each month. Please contact the editors at jking2005@shaw.ca, (250) 595-3892. The editors reserve the right to edit and cut articles in the interest of space.

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HepCBC

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#### LETTERS TO THE EDITOR

The hepc.bull welcomes and encourages letters to the editor. When writing to us, please let us know if you do not want your letter and/ or name to appear in the bulletin.

## NO RISK FACTOR? THINK AGAIN

Researchers in South Italy investigated the role hairdressers might play in spreading blood-borne diseases. They set out to survey a random sample of 105 hairdressers in 2008, who remained anonymous. That HIV and hepatitis could be spread by razors was known by 93.3%, but even so, gloves were often not available, 30% didn't use them, and half of those re-used them. 90 of them sterilized their tools with UV light, but only 20 did so between customers, and only slightly more than a third of them disinfected brushes daily. The younger operators knew more about preventing transmission, especially if they studied beyond primary school. Only 32 participated in a free course about avoiding occupational risk, given by the U. of Palermo. The researchers concluded that health messages need to improve and be available to the general population, and that obligatory refresher courses should be organized for hairdressers.

Source: www.ncbi.nlm.nih.gov/ pubmed/19892853

# WHD 2015 **VICTORIA, BC**

A number of local groups joined to commemorate this day with an afternoon of speeches, a march to Parliament Building, and educational exhibits. In the evening, the Parliament Building was lit up in red and yellow for the first time, and there was an open microphone for people to share their experiences with hepatitis C and their memories of people lost due to liver dis-

British Columbia Parliament Buildings. Photo at night, Barbara

Pedrick

ease.





Photo twilight, CD Mazoff.

(Continued on page 3) --->

# CAN'T AFFORD TREATMENT?

We receive one or more calls a week from people who are desperate. They need treatment. They can't afford it. Some aren't "sick enough." Way too often, we have to tell them that the treatment that they need isn't available or is not covered yet, encouraging them with the fact that it will be...soon.

You may have heard that some people have been travelling to India to obtain generic hepatitis C drugs. Below is a link to an Australian news report which tells the story of Greg Jefferys, who did just that. He became a 'medical tourist', buying generic hepatitis C drugs at a fraction of the price by travelling to India. Mr Jefferys also decided to blog about his experience and facilitate the path of others in their quest for treatment. You can read his blog and his treatment journey by clicking the links below. His story is very interesting and it raises some important issues about access to hepatitis C treatment.

But is it safe to buy these sophisticated, strong drugs by travelling to India or purchasing them by mail order? To begin with, it is illegal in Canada to import prescription drugs by mail or courier. But let's say you travel to India. How will you know that what you buy is not fake? Even more importantly, assuming the drugs you buy are authentic, how will you ensure your treatment is supervised by a specialist? People undergoing hepatitis C treatment require monitoring throughout their treatment. Moreover, while the new drugs are available, they haven't been used long enough to be sure of all of the interactions. Wherever you are, hepatitis C drugs require a prescription, both to acquire them, to bring them into Canada, and to take them. You must ensure you comply with all aspects of the law.

These are all essential considerations if you become tempted to travel the same journey as Greg Jefferys. Please note: We are not qualified to give advice or to comment on Mr Jeffervs' actions. You should make treatment decisions in conjunction with your doctor or specialist.

Links: (www.abc.net.au/news/2015-08-20/hepatitis-csufferer-imports-life-saving-drugs-from-india/6712990). and

http://blogs.hepmag.com/gregjefferys/

http://hepatitisctreatment.homestead.com/index.html

**DID YOU HAVE POLIO SHOTS** WHEN THEY FIRST CAME OUT? **GET TESTED!!** 

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# WHD 2015 VICTORIA, BC (contd.)



Susan Malloch, sharing memories of the life and recent loss of her partner, Allen McCulloch, urged every Baby Boomer to get tested and treated for hepatitis C before their liver gets badly damaged.



Hepatitis C Advocate Karen Felske sharing her lived experiences with hepatitis C treatment and liver cancer. Her strong, positive message inspired us all.



Aboriginal people freely sharing information about hepatitis C was a big part of this day. Woman above is holding educational materials for First Nations from the BC Centre for Disease Control.



Douglas Laird, Victoria-based Hepatitis C Activist and writer, spoke from his heart. Thanks DOUGLAS! Credit: CD Mazoff

Hermione Jefferis (below left) of AVI has been the Chief Organizer of World Hepatitis Day Victoria for several years. THANKS, HERMIONE! Credit: CD Mazoff



### WHD 2015 AROUND CANADA



Smilin' Sandi in **Oshawa**, **ON** invited anyone wishing to promote HCV awareness to drop by her workplace. It's amazing what even one person can do! She had lots of chairs to sit at the front of the store.

"I do my best to serve my customers first and then share my personal cause. I have over 20 baskets this year. So far I have collected \$75 in donations for OCHC. I will continue the raffle until September. I have encouraged people to get tested, met some people who have family or friends with Hep C, recently diagnosed individuals, and a lot of people uneducated about HCV. Links, etc., can be found on my main page of Sandi's Crusade Against Hepatitis C:

http://www.creativeintensity.com/smking/

#### LIGHTING UP!

This year the following landmarks were lit up: The CN Tower, The Canadian and American sides of Niagara Falls, Skylon Tower in Niagara Falls, The Heritage Building Ottawa, Halifax City Hall, BC Legislature in Victoria, BC Place Stadium and Science World Vancouver. Can you think of a place to light up next year? Let us know: info@hepcbc.ca #LightsUp4Hep



Science World Vancouver



Niagara Falls http://whdcanada.org/ news/



CN Tower -<u>http://</u> <u>whdcanada.org/</u> <u>news/</u>



BC Place: WHD Vancouver Comm.

# DAKLINZATM APPROVED by HEALTH CANADA

August 20, 2015: Today we received news that another upcoming drug, daclatasvir (Daklinza<sup>TM</sup>) from Bristol-Myers Squibb, has received a Notice of Compliance from Health Canada. Approved for GT 1-2 (conditionally for 3), it is also being considered for coverage by BC Pharmacare, though not yet approved. This drug is unique in its potential to mix and match with other drugs in order to treat a variety of genotypes, including hard-to-treat genotype 3 with Gilead's (combined sofosbuvir [Sovaldi<sup>TM</sup>]). Though BMS could have combined it with one or more of its own drugs, it chose to submit daclatasvir on a stand-alone basis which could be combined with drugs from other companies, which is what HepCBC has been advocating that pharmaceuticals should do whenever possible, in order to quickly give physicians the option to treat individual patients according to their unique circumstances and the most recent clinical research. Read full press release: http://www.newswire.ca/news-releases/healthcanada-approves-daklinza-daclatasvir-for-thetreatment-of-chronic-hepatitis-c-infection-acrossmultiple-genotypes-including-genotype-3-522375441.html

(Holkira Pak<sup>TM</sup> —Continued from page 1) weeks in most cases, 24 weeks max.) is so short that patients generally do not suffer the severe ribavirin side-effects reported in the longer (48 week) treatments patients used to endure. For more information see Product Monograph:

http://www.abbvie.ca/content/dam/abbviecorp/ca/english/docs/ HOLKIRA\_PAK\_PM\_EN.pdf and BC government press release: https://news.gov.bc.ca/ releases/2015HLTH0053-001186

# PATIENT INPUT NEEDED: ABBVIE 2D—GENOTYPE 4

For hard-to-treat Genotype 4 patients, here is exciting news! A new AbbVie product may soon be available for you. Health Canada has called for Patient Group Input into this special combination which contains the same drugs in Holkira Pak<sup>TM</sup> except there is no dasubuvir. Approved under the name Technivie<sup>TM</sup> in the USA, this treatment has shown 91% efficacy without ribavirin added and 100% with ribavirin. To contribute patient input: <a href="http://hepcbc.ca/2015/08/pt-input-abbvie-gt4/">http://hepcbc.ca/2015/08/pt-input-abbvie-gt4/</a>

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#### **CONFERENCES**

#### The Viral Hepatitis Congress 2015

10–12 September 2015 Frankfurt, Germany www.viral-hep.org/

#### **AFEF 76<sup>th</sup> Meeting 2015 (AFEF 2015)**

30 Sep—3 Oct 2015 Toulouse, France www.afef.asso.fr/congres/afef2015/ index.phtml

#### National Hispanic Hepatitis Awareness Day

15 October 2015 Worldwide

www.hispanichepatitisday.org/

# 2<sup>nd</sup> International Hepatitis Cure & Eradication Meeting

November 2015
Vancouver, Canada
www.virology-education.com/event/
upcoming/2nd-international-hepatitis-cureeradication-meeting-2015/

#### **AASLD - The Liver Meeting**

13 - 17 November 2015 San Francisco CA www.aasld.org

# APASL Single Topic Conference: HCV in India Conference 2015

18-20 December 2015 New Delhi, India http://apaslindia.com/index.html

# The 5<sup>th</sup> Canadian Symposium on HCV

In building upon the success of last year's meeting, we look forward to expanding the discussion on HCV-related issues in Canada. The theme of this year's symposium is "We're not done yet: Remaining Challenges in Hepatitis C".

Confirmed international invited speakers are the following:

Andrea Cox, Johns Hopkins University, Baltimore, USA (Biomedical Sciences)

David Nelson, University of Florida, Florida, USA (Clinical Sciences)

Matthew Hickman, University of Bristol, Oakfield Grove, UK (Epidemiology and Public Health)

Manal El-Sayed, Ain Shams University, Cairo, Egypt (Social Sciences)

We look forward to seeing you on February 26, 2016 at the Fairmont Queen Elizabeth, Montréal, QC. If you have any questions, please do not hesitate to contact Norma Choucha: ncrtp.hepc@gmail.com.

# THANKS!!

HepCBC thanks the following institutions and individuals for their generosity: The late John Crooks, Allison Crowe, Billie Wood and Adrian, Victoria Positive Living Centre, Provincial Employees Community Services Fund, the Victoria Foundation, Dr. C. D. Mazoff, Judith Fry, and the newsletter team: Beverly Atlas, Diana Ludgate, Alp, Cheryl, Anamaria, and S.J.

Please patronize these businesses that have helped us: Top Shelf Bookkeeping, Merck Canada, Bristol-Myers Squibb, Roche Canada, Vertex, Gilead, Janssen, Boehringer-Ingelheim, AbbVie, Rx&D, VanCity, Country Grocer, and Thrifty Foods.

#### (ALLEN —-Continued from page 1)

companions. A celebration of Allen's life was held on Saturday, August 15, 2015 at the S.V.I. Rangers Hall at 3498 Luxton Rd off Happy Valley Rd., 1:00-4:00pm. Sincere thanks to the staff at Coolaid Clinic Victoria, HepCBC (where Allen was a valued board member), and 4 south RJH. If desired, any donations to HepCBC in Allen's honour would be much appreciated.

Source: www.legacy.com/obituaries/timescolonist/obituary.aspx?n=allen-glen-

mccul-

loch&pid=175405044#sthash.1QtJiylS.4kEJZWbe.dpuf

#### **HEPCBC AGM**

Tuesday September 22<sup>nd</sup>, 2015 7:00 PM 1947 Cook Street, Victoria, BC (Victoria Health Unit, Activity Room)

#### **SCHEDULE**

**7:00- 7:30 PM** Welcome and Presentation by Roz Milne, hepatology nurse from Cool Aid Society, about "Cooperative Efforts Between our Organizations: Current and Potential"

7:30-8:30 PM Annual General Meeting

#### **AGENDA of Annual General Meeting**

Approve minutes of AGM 2014
Financial Report
Set number of directors, introduce slate
Election of those directors
President's Report
Coordinator and Staff Report
Adjourn

#### DETAILS

Refreshments provided. Members of the public are welcome. No charge.

Hope to see you there!

NEW!! UPDATED!!
Peppermint Patti's
FAQs,
Version 10.1!!

Download for free:

<a href="http://hepcbc.ca/wp-content/">http://hepcbc.ca/wp-content/</a>

<a href="mailto:uploads/2015/04/">uploads/2015/04/</a>

FAQ v10 1.pdf

# HEPCBC LIVER WARRIORS 5<sup>TH</sup> YEAR AT THE MARATHON

Fighting HCV stigma, demonstrating the benefits of exercise for liver health, getting in shape, meeting new people, having fun, raising HCV awareness—that's what being on the Liver Warriors team is about. 2015 is the fifth vear of the HepCBC Liver Warriors team at the GoodLife Fitness Victoria Marathon. This year the event will occur Sunday, October 11th, wending through Victoria's heritage downtown, into its elegant older neighbourhoods and gardens, and along its pristine beaches. There! So now you're coming, right? This is not just a marathon, but you can choose to do a half-marathon and an 8k race. as well. People are welcome to either walk or run, but if you're a serious runner, this one is

as well. People are welcome to either walk or run, but if you're a serious runner, this one is a "Boston Marathon Qualifying" course. Consider making the commitment to join our team this year. It's an amazing feeling, flying over that finish line!

Take a look at the site now:

www.runvictoriamarathon.com/register.aspx

If you decide to go for it, be sure to join the "HepCBC Liver Warriors" team. It's on the 1/2 Marathon site already, so just select it from the dropdown list. For other events, you may have to create the team name yourself. Please let HepCBC know if you join the team by writing us at

marathon.hepcbc@gmail.com .

Regular Prices to Sept. 15th (which include a race T-shirt) are as follows:

- •1/2 Marathon (21.1 km) \$85
- •Full Marathon (42.2 km) \$110
- •8k Road Race \$45

Hope you will decide to join our team!



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# LEADERS GET TESTED FOR HEPATITIS C

HepCBC wants to thank Elizabeth May, MP (Saanich-Gulf Islands riding) who decided to get publicly tested for hepatitis C on July 29, 2015, the day following World Hepatitis Day (July 28th every year). In the video below, she explains why.

We also wish to thank Roz Milne, RN with Cool Aid Society in Victoria who performed the testing. Ms. May joins at least one other MP (Murray Rankin), 13 MLAs, 2 mayors and numerous City Councilors who have taken this courageous step.

In addition, Dr. Evan Adams, Chief Medical Officer of the First Nations Health Authority also decided to take this step in hopes of demonstrating his commitment to doing whatever he can to conquer hepatitis C which is unusually prevalent among aboriginal populations. Dr. Alexandra King performed the test.

See videos of these three brave leaders: being tested for hepatitis C and explaining why.

#### Dr. Evan Adams VIDEO

https://www.youtube.com/watch?v=9Dh1Svkn1g

#### MP Elizabeth May VIDEO

https://www.youtube.com/watch?v=q20pYTMVAo

#### **MP Murray Rankin VIDEO**

https://www.youtube.com/watch? v=NTBA9g64LEU



MP

(Saanich-Gulf Islands) Elizabeth May on July 29, 2015, Victoria.



Chief Medical Officer, First Nations Health Authority, Dr. Evan Adams on July 10, 2015, Vancouver.

#### SVR HONOUR ROLL

12 weeks after treatment? Give others hope. Add your name! Congratulations to our friends:

- 1. GJ SVR Dec 1998 IFN/RBV 52 wks Dr. Anderson / Natalie Rock, Vancouver, BC.
- 2. Jeanie Villeneuve Oct 2000 Schering IFN/RBV
- 3. Amberose (GT2a/2c) SVR 2000 Schering IFN/RBV 24 wks
- 4. KG-Transfused 1987 (treatment naïve GT2A/2C) IFN/RBV 24 wks, 2003-2004, Toronto. SVR confirmed 2014
- 5. Darlene Morrow (GT1 relapser) Mar 2004 - Hyperthermia/Induction + pegIFN/RBV.
- 6. Kirk Leavesley (GT1) 2004 Roche 7. **Beverly Atlas** - (GT1a) - 2005/2006
- Albuferon/RBV 44 wks 8. Steve Farmer - 2008 (Transplant Van-
- couver 2005) IFN/RBV 72 weeks. 9. Gloria Adams† - (GT1b relapser) - Fall 2009 IFN/RBV/telaprevir 48 wks - Drs. Erb & Yo-
- 10. Don Crocock (GT1 Stage II) Dec. 2010 IFN/RBV - 48 weeks

shida, Vancouver, BC)

- 11. **Daryl Luster** (GT1a) Feb 2011 IFN/RBV/RO5024048 48 wks.
- 12. Donna Krause (GT1 partial responder) SVR Nov 2011- Pegasys/Copegus, danoprevir/ ritonavir/R05024048 24 wks. Dr. Erb, Vancou-
- 13. Hermione Jefferis (GT 1a) SVR 2011, PegIFN/RBV, 48 wks, Dr. Partlow, Victoria, BC
- 14. Cheryl Reitz (GT1b previous partial responder) SVR12 Mar 2013 - asunaprevir/ daclatasvir 24 wks - Dr. Ghesquiere, Victoria,
- 15. Anita Thompson (GT1a treated 3 times) Cirrhosis - Apr 2013 - Pegasys/boceprevir 48 wks. Dr. M. Silverman, Whitby, ON.
- 16. Leon Anderson (GT2 partial responder) SVR24 May 8, 2013 - GS-7977/RBV 16 weeks 31. Wendy Mackay [NEW] Transfused - Dr. Alenezi & Dr. Conway- VIDC - Vancouver.
- 17. Joan King (GT1b treated 5 times) SVR24 June 2013 - asunaprevir/daclatasvir 24 wks Dr. Ramji, Vancouver, BC
- 18. Jackie GT1 relapser) SVR24 June 2013 - IFN/RBV/boceprevir 48 wks. Dr. Keith Bovell, Guelph, ON.

- Have you been undetectable for at least 19. Sandy J. (GT 1a treatment naïve) Oct 31, 2013 - IFN/RBV/Victrellis 28 wks. Fran Faulkner, RN, Vancouver Island. Now SVR24.
  - 20. Andrew P. (GT 1a many prev treatment attempts over 10+ years, including Incivek Jan 2014.) sofosbuvir/ledipasvir + RBV 24 wks
  - 21. Peter A Walker (GT1a, treatmentnaïve) SVR Jan 2014 - PegIFN/RBV +boceprevir (Eprex-for low RBC count from
  - 22. Diane Stoney Transfused 3/21/79 (GT 1a treatment naïve) Feb 4 2014 - 12 wks placebo, then 12 wks on ABT-450/r+ABT-267+ABT-33+RBV. Dr. Tam, Vancouver, BC
  - 23. Coreen Kendrick (GT1a treatment naïve) Mar 10, 2014 MK5172/MK8742 12 weeks Dr. Ramji, Vancouver, BC.
  - 24. Jack Swartz—(Treated 3 times) Apr 2014 IFN/RBV/Victrelis, Dr. S. Wong, WHSC.
  - 25. Del Grimstad July 2014, 12 weeks simeprevir/Sovaldi
  - 26. Linda May (GT1b transfused, treatment-naïve) 12 wks asunaprevir/ daclatasvir, Dr. Tam, LAIR Centre.
  - 27. **Robin Tomlin** (GT1 treatment-naïve) SVR12 May 4, 2014 --Harvoni 12 weeks--Dr. Yoshida VGH.
  - 28. **Bob** (GT1a/HIV relapser) SVR24 Nov 2014 pegIFN/RBV/Incivek 24 wks, Dr. Montaner, Salt Spring Island, BC.
  - 29. Nancy Neel (GT1a previous relapse IFN/RBV 48 wks) SVR24 Mar 2015 MK-5172/MK 8742 12 wks. Dr. Ramji, Richmond. BC.
  - 30. Sandra Newton [NEW] (GT1a treatment-naïve, infected 1984) SVR12 Aug 2015. Harvoni 8 wks. Dr. David Pearson, Victoria, BC
  - 1971(GT1a prev 48 wks Victrelis Triple) Cirrhosis—SVR24 Aug 2015, 24 weeks Harvoni, Dr. Tam, LAIR Centre

Please send your name and info to Joan at info@hepcbc.ca

See http://www.generationhep.com for info about the 1945-1965 population and why members should get tested for hepatitis C. A project of Canada's World Hepatitis Day 2015 Committee. (HepCBC, BCCDC, Pacific Hep C Network, First Nations Health Au-



thority, and Purpose Society). Look to their website for great ideas and resources for promoting Baby Boomer testing.



# DIANE PARSONS FORSYTHE DEPARTED AUGUST 1, 2015

Diane Parsons, led the Canadian Hep C tainted blood class action lawsuit. She fought valiantly as the lead plaintiff for those transfused between 1986 abd 1990. (See <a href="http://www.cbc.ca/news/canada/nova-scotia/diane-parsons-who-led-hep-c-tainted-blood-lawsuit-dies-in-halifax-">http://www.cbc.ca/news/canada/nova-scotia/diane-parsons-who-led-hep-c-tainted-blood-lawsuit-dies-in-halifax-</a>

<u>1.3179767</u>) She was only 64. She had received a transfusion for dental surgery in 1989. She became very ill, and the complications of hepatitis C precipitated her death, according to her doctor.

Harvey T. Strosberg, the lead lawyer for the case., was quoted, "She was a visionary and a leader. She put her faith in the judicial system and she was not disappointed. Thousands of Canadians have benefited because she led the way," he said.

# TRANSFUSED 1986-1990? MORE INFO...

**Anyone who was diagnosed before June 30, 2007** must have made a claim within 3 years of diagnosis or by June 30, 2010 whichever was later.

Anyone diagnosed after June 30, 2010 must make a claim within 3 years of diagnosis

**Secondarily infected persons** (spouses or children of primarily infected persons) must make a claim within 3 years of the primarily infected person's claim.

# **IMPORTANT FOR CLASS MEMBERS 1986-1990**

The Joint Committee has a mandate to implement the 1986-1990 Hepatitis C Settlement Agreement and to supervise the ongoing administration of claims. Every three years, we also review the financial sufficiency of the Trust Fund to ensure that it is adequate to meet the expected needs of Class Members and Family Class Members.

WHY WE WANT TO HEAR FROM YOU On the most recent financial sufficiency review, the actuaries retained by the Joint Committee and the federal government expressed the opinion that the Trust Fund is sufficient to meet the expected needs of Class Members and Family Class Members and there is a surplus. The surplus is estimated to be between \$236 million to \$256 million. The orders approving the settlement allow the Joint Committee and the governments to apply to the Courts where there is a surplus. The Courts have discretion to decide what to do with the surplus. They can also decide that all or a portion of the surplus should be kept in the Trust Fund. The Joint Committee will be making an application to the Courts to request that all or a portion of the surplus be allocated in favour of Class Members and Family Class Members. The Joint Committee wants your input on the areas of the settlement that you feel fall short and how you think the surplus should be used. The Joint's Committee's application and any application made by the federal government regarding the surplus will be considered by the Courts at a Joint Hearing that will take place in Toronto, Ontario on June 20-22, 2016. There will be a video link of the hearing to a court room in British Columbia where the public can attend. A schedule of the steps leading up to the Joint Hearing is attached. For up-to-date information, to see the documents filed with the Courts, and for the location of the hearings go to www.hepc8690.ca.

HOW YOU CAN PROVIDE YOUR INPUT Members of the Joint Committee will be holding consultation sessions in various cities in English and French, some of which will be webcast live on the internet. You may also make a written submission. You can provide your input in 3 ways:

--by attending a consultation session in person at the places and times listed below. Additional sessions may be announced, so visit <a href="http://www.hepc8690.ca">http://www.hepc8690.ca</a> for further updates. If you plan to attend in person, please let us know in advance by calling 1.866.228.0073 or emailing <a href="https://www.hepc8690.ca">hepc@strosbergco.com</a> so that we know how many people to expect for planning purposes S

--by watching a webcast consultation session live on the internet, which will allow you to ask questions and make comments while the session is taking place. To participate in any of the webcast consultation sessions, please go to <a href="http://www.postelvideo.com/webcast/single3/login.php">http://www.postelvideo.com/webcast/single3/login.php</a>. On the day of the session, sign in with your name, email address and use the password hepc

--by calling or writing a member of the Joint Committee, whose contact information is listed below. Written submissions sent to a Joint Committee member will receive serious consideration and may be provided to the Courts for their consideration at the Joint Hearing

#### CONSULTATION SESSIONS

Additional sessions across the country may be announced. Visit <a href="http://www.hepc8690.ca">http://www.hepc8690.ca</a> for updates and more info such as where to send submissions, names of committee members, submission deadlines, etc.

The personal representatives and family members of deceased persons who died of hepatitis C must make claims within 3 years of the date of death.

Persons who first applied under the pre-86 post-90 settlement but were rejected from that settlement because they were infected between 1986 and 1990 must apply within 3 years of that rejection.

More information on these deadlines can be found on the Administrator's website in the "protocols" section at:

http://www.hepc8690.ca/content/documents/CAPs/index-e.shtml

In addition, the Administrator is "registering" people who have missed these deadlines in case the courts permit some or all such persons to apply in the future. Class Counsel previously made an application but did not succeed. Another application may be made as part of the surplus applications.

Class Members: See details on this website:

http://www.hepc8690.ca/PDFs/Important% 20Notice/Notice%20to%20Class% 20Members%20%202015.pdf

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#### ABBVIE CARE

With the approval of HOLKIRA PAKTM, AbbVie is launching AbbVie Care, which is a program that will provide best-in-class solutions to improve outcomes for people living with hepatitis C.

Canadians prescribed HOLKIRA PAKTM will have the opportunity to request to be enrolled in AbbVie Care. The signature care program is designed to provide a wide range of customized services including reimbursement assistance, education and ongoing disease management support. AbbVie Care will not only support health care professionals but people living with genotype 1 hepatitis C throughout their treatment journey to achieve high cure rates in the real world.

For enquiries: 1-844-471-2273.

#### **NEW! -- CLAIRE**

Bristol-Myers Squibb Canada has created Claire, a patient support program designed to provide patient health information and reimbursement assistance for patients who have been prescribed DAKLINZA<sup>TM</sup> (daclatasvir). This personalized patient support program represents a service offered at no cost to the patient and is fully confidential. It will be available to patients once the product is commercially available, which is expected before the end of September. Once it is available, you can call the information line for more details at: 1-844-428-2559. Should you have medical enquiries regarding DAKLIN-ZA<sup>TM</sup>, please contact our Medical Information Department at 1-866-463-6267.

#### MOMENTUM<sup>TM</sup> SUPPORT

To learn more about SOVALDITM, HAR-VONITM or the Momentum Program<sup>TM</sup> in Canada, the patient should speak to his/her doctor or nurse or call the Gilead Sciences Canada medical information line at 1 855 447 7977. Eligible patients may receive an integrated offering of support services for patients and healthcare providers throughout the entire treatment journey, including:

- ·Access to dedicated case managers/ reimbursement navigators to help patients and their providers with insurance-related needs, including identifying alternative coverage options through private, federal and provincially-insured programs.
- •The SOVALDITM/HARVONITM Co-pay assistance program, which will provide financial assistance for eligible patients who need help paying for out-of-pocket medication costs.
- Medication delivery services.

### MERCK CARETM

MerckCare<sup>TM</sup> is a program to help people who have been prescribed PEGETRON<sup>fM</sup>, VICTRELIS<sup>TM</sup> or VICTRELIS TRIPLE<sup>TM</sup>. The program provides:

- ·assistance with reimbursement and/or insurance claims.
  - •financial assistance for co-pay/ deductible for people who qualify.
  - •24/7 nursing support by phone. •multilingual assistance.

  - •home delivery of medication.

MerckCare<sup>TM</sup> provides all of these services free of charge.

To enroll in MerckCare<sup>TM</sup>, you can call 1-866-872-5773 or your doctor or nurse can submit an enrollment form for you. Reimbursement specialists are available from 8:00 a.m. to 8:00 p.m. EST Monday to Friday, excluding statutory holidays.

#### **PEGASSIST**

The PegAssist Reimbursement Assistance Program provides reimbursement coordination assistance for patients who have been prescribed Pegasys or Pegasys RBV. The program will assist in securing funding for patients to ensure that they can start, stay on, and complete their treatment successfully. PegAssist Reimbursement Specialists are available (Monday to Friday, 10 AM - 6 PM EST) by calling: 1-877-PEGASYS or 1-877 -734-2797. Patients can also obtain a program enrollment form from their nurse/physician to gain access to the pro-

The program provides financial aid to qualified patients, alleviating financial barriers which may prevent patients from starting treatment, i.e., deductibles and/or copayments. In partnership with CALEA Pharmacy, the program can conveniently deliver the medication directly to patients' homes or to the clinics.

#### **INCIVEK CARE**

Vertex's INCIVEKTM Care Patient Assistance Program supports patients with the reimbursement process for INCIVIKTM (telaprevir) treatment (INCIVIK<sup>TM</sup>, pegIFN, ribavirin). It will give you an efficient assessment of your options and eligibility. You may qualify to receive co-payment and other financial assistance to supplement www.hepc8690.com your private and provincial drug program coverage. The program also provides dispensing and home delivery options, and expert treatment advice. Call the Support Line at 1-877-574-4298. (Select option 2 for English, then 2 for INCIVIK™ Care.)

#### IBAVYR<sup>TM</sup>

Pendopharm established has IBAVYR<sup>TM</sup> Patient Support Program. program will assist patients who have been prescribed IBAVYR<sup>TM</sup> (ribavirin tablets) with reimbursement navigation, financial assistance and pharmacy services. managers will support patients with insurance-related matters and assess eligibility for financial support. Pharmacy services include adherence support, medication delivery and counselling.

To enquire or to enroll, you may call 1-844-602-6858 Monday-Friday 7am to 11pm

### **BIOADVANCE®**

JANSSEN's GALEXOS<sup>TM</sup> (simeprevir) BioAdvance® program can assist you in many ways during your treatment. This includes compiling and submitting, on your behalf, all the forms and documents required by your insurance company to request coverage of GALEXOSTM, and following up with your insurer to get you the best coverage possible. If you don't have private insurance, the GALEXOSTM: BioAdvance® program will investigate public assistance programs that can help pay for your treatment. Whichever type of coverage you have, if your insurance does not fully cover the cost of treatment, the GALEXOSTM: BioAdvance® program can usually coordinate and provide financial assistance to help you get treated. Finally, the program can offer many other types of support and your doctor and members of your healthcare team will work with the GALEXOSTM: BioAdvance® Program to develop a customized approach to best support you throughout the course of your treatment. Contact: 1-855-512-3740.

#### COMPENSATION

Class Action Suit Hotline: 1-800-229-5323 ext. 8296 Health Canada Compensation Line: 1-888-780-1111 Red Cross Compensation pre-86/post-90 Registra-

tion: 1-888-840-5764 <u>Hepatitis C@kpmg.ca</u> Ontario Compensation: 1-877-222-4977 **Quebec Compensation:** 1-888-840-5764

#### **CLAIMS ADMINISTRATOR 1986-1990**

Claimants may be reimbursed for costs of treatments and accepted hepatitis C medications not covered by public or private healthcare plan while they wait for reimbursement from the 1986-1990 plan.

Administrator 1-877- 434-0944 info@hepc8690.com

#### Pre-86/Post-90

Administrator 1-866-334-3361 preposthepc@crawco.ca www.pre86post90settlement.ca

Settlement Agreement: www.pre86post90settlement.ca/PDFs/SA/

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#### **SUPPORT BC/YUKON**

**Armstrong** HepCURE Phone support 1-888-437-2873

AIDS Vancouver Island The following groups provide info, harm reduction, support, education and more:

• Campbell River: Drop in, harm reduction, needle exchange, advocacy. 1371 C - Cedar St.

Contact leanne.wingert@avi.org 250-830-0787

• Comox Valley Harm reduction, counselling, advocacy. 355 6<sup>th</sup> St., Courtenay. Contact Sarah

sarah.sullivan@avi.org 250-338-7400

• Nanaimo AVI Health Centre. Counseling, advocacy. NEW: 102-55 Victoria Rd Contact Anita for details. 250-753-2437

anital.rosewall@avi.org

• Port Hardy (Port McNeil, Alert Bay, Port Hardy, Sayward, Sointula and Woss) Drop-in kitchen. 7070 Shorncliffe Rd. Contact Shane, 250-949-0432 shane.thomas@avi.org

•Victoria Access Health Centre, drop in, disability applications, peer training. Support group Tues 12:30 PM, 713 Johnson St., 3rd floor, 250-384-2366 <u>Hermione jefferis@avi.org</u>

**ANKORS Hepatitis C Project** 

Hep C Info, support for prevention, testing, treatment and living well with Hep C.

Boundary, Nelson, West Kootenay Women's gathering monthly. 101 Baker St, Nelson. Contact Laura 1-800-421-2437 250-505-5506 <a href="mailto:ankorshepc@ankors.bc.ca">ankorshepc@ankors.bc.ca</a>
 East Kootney 209 16th Ave N, Cranbrook,

• East Kootney 209 16th Ave N, Cranbrook, Contact Michelle 250-426-3383 1-800-421-2437 ankorshcv@gmail.com

Castlegar Contact Robin 250-365-6137 eor@shaw.ca

Chilliwack PCRS Hep C Prevention, harm reduction. 45904 Victoria Avenue, Chilliwack. Contact Kim Lloyd 604-798-1416. <a href="mailto:lbirdsall@pcrs.ca">lbirdsall@pcrs.ca</a> <a href="mailto:www.pcrs.ca">www.pcrs.ca</a>

Comox Valley Positive Wellness North Island Treatment/Pre & Post-treatment Support Group 2<sup>nd</sup> & 4<sup>th</sup> Wed., 615-10th St, Courtenay. Lunch. Contact Cheryl 250-331-8524. Cheryl.taylor@yiha.ca

CoolAid Community Health Centre, Victoria. Meetings each Wed 10 AM and Thu 1:30 PM. 713 Johnson St. Support for all stages of treatment (deciding, during, after). Contact Roz <a href="milne@coolaid.org">milne@coolaid.org</a> for treatment or group info.

**Courtenay HCV Peer Support and Education.** Contact Del 250-703-0231 <u>dggrimstad@shaw.ca</u>

**Cowichan Valley HCV Support** Contact Leah 250-748-3432 <u>r-l-attig@shaw.ca</u>

Haida Gwaii support. Contact Wendy

wendy@wendyswellness.ca www.wendyswellness.ca

**HepCBC** <u>info@hepcbc.ca</u>, <u>www.hepcbc.ca</u> Call for office hours.

•Victoria Peer Support: 4<sup>th</sup> Tues. monthly 7-8:30 PM, Victoria Health Unit, 1947 Cook St. Contact 250-595-3892 Phone support 9 AM-10 PM. •Fraser Valley Support/Info: 604-576-2022

Kamloops ASK Wellness Centre. Chronic illness health navigation/support.

<u>info@askwellness.ca</u> 250-376-7558 1-800-661-7541 ext 232 or Merritt health housing & counseling 250-315-0098

www.askwellness.ca

**Kamloops** Hep C support group, 2<sup>nd</sup> and 4<sup>th</sup> Wed monthly, 10-1 PM, Interior Indian Friendship Society, 125 Palm St. Kamloops. Contact Cherri 250-376-1296 Fax 250-376-2275

Kelowna Hepkop: Phone support, meeting info.

Contact Lisa 1-866-637-5144 <u>limortell@shaw.ca</u>

Nanaimo - Central Island Hepatitis Service: Nurses & doctors available for info, support, treatment. Clinic located in Nanaimo. Doctor or self-referral. Contact 1-855-740-2607, sarah.hughes@viha.ca or shelby.munk@viha.ca

New Westminster Stride with Purpose "HepC" Support Group 1st & 3rd Fri monthly 10:30-11:30. BBP Nursing Team, refreshments/lunch. Contact: Stride Workers -526-2522, mail@purposesociety.org

Positive Wellness North Island-North Island Liver Service Info, support, treatment/prepost treatment groups. Doctor or self-referral. 1-877-215-7005 250-850-2605.

•Courtenay: 2<sup>nd</sup> Fri monthly 1PM, Drop-in, Comox Valley Nursing Centre (nurse)

• Campbell River: Treatment/pre&posttreatment support group 1st & 3rd Thu monthly 10-12 noon, Discovery Room, Sunshine Wellness Centre, Campbell River Hospital. Jody Crombie at 850-2620, jody.crombie@viha.ca

Penticton & District Community Resources Society, Harm Reduction Program, Meetings every 2nd Tues, 12:30-1:30 PM. 330 Ellis Street. Contact Melanie: 250-488-1376 or 250-492-5814

**Positive Haven** Info, harm reduction, support, drop in, clinic. 10697 135A St. Surrey. Contact Monika 604-589-9004.

Positive Living Fraser Valley (Abbotsford) Hep C support, Drop-in centre #108-32883 S. Fraser Way, M-F 10:30 AM-4:30PM. Info, support worker, rides to appointments in surrounding areas. Contact 604-854-1101 or <u>plfvcentre@plfv.org</u>

**Powell River Hepatology Service** Powell River Community Health, 3<sup>rd</sup> Floor–5000 Joyce Ave. Contact Melinda 604-485-3310 *Melinda.herceg@ych.ca* 

**Prince George Hep C Support** Contact Ilse <a href="mailto:ilse.kuepper@northernhealth.ca">ilse.kuepper@northernhealth.ca</a>

Sunshine Coast-Sechelt Healthy Livers Support Group Information/resources
Contact Catriona 604-886-5613
<a href="mailto:catriona.hardwick@vch.ca">catriona.hardwick@vch.ca</a> or Brent
604-740-9042 <a href="mailto:brent.fitzsimmons@vch.ca">brent.fitzsimmons@vch.ca</a>

**VANDU** The **Vancouver** Area Network of Drug Users. 380 E Hastings St. M-F 10-4 Contact 604-683-6061

vandu@vandu.org www.vandu.org

Vancouver HCV Support Contact Beverly 604-435-3717 <u>batlas@telus.net</u>

Vancouver Hepatitis C Support Group Contact 604-454-1347 or 778-898-7211, or call 604 -454-1347 (Terry), to talk or meet for coffee.

**Vernon telephone buddy,** M-F 10-6 Contact Peter, <a href="mailto:pvanbo@gmail.com">pvanbo@gmail.com</a> Tel. 250-309-1358.

**YouthCO** HIV and Hep C Society of BC. Call for appts or drop in M-F 10-6. 205-568 Seymour St,

Vancouver 604-688-1441, 1-855-YOUTHCO Stew art <u>info@youthco.org</u>, www.youthco.org

Whitehorse, Yukon—Blood Ties Four Directions Contact 867-633-2437 1-877-333-2437 admin@bloodties.ca

To list Canadian groups here, please send your details to <u>info@hepcbc.ca</u> It's free!

#### **OTHER PROVINCES**

<u>ONTARIO:</u> Barrie Hepatitis Support

Contact Jeanie for info/appointment

jeanievilleneuve@hotmail.com

Hamilton Hepatitis C Support Group 1st Thurs. monthly, 6-7 PM, Hamilton Urban Core Community Health Centre, 71 Rebecca St, Hamilton. Contact Maciej Kowalski, Health Promoter 905-522-3233 mkowalski@huechc.com

Hep C Team, AIDS Committee of North Bay & Area. Education, outreach, treatment, individual & group support, harm reduction, needle exchange. 269 Main St. W, Suite 201, North Bay. Contact 705-497-3560, 1-800-387-3701 or hepccommcoord@gmail.com.

Hepatitis C Network of Windsor & Essex County Last Thurs. monthly, 7 PM, Teen Health Centre-Street Health Program Office, 711 Pelissier St., Suite 4, Windsor. Contact Andrea Monkman 519-967-0490 or

hepcnetwork@gmail.com. http://hepcnetwork.net

<u>www.aidsnorthbay.com</u>

Kingston Hep C Info HIV/ AIDS Regional Service. Contact 613-545-3698, 1-800-565-2209 <u>hars@kingston.net</u> <u>www.hars.ca</u>

**London Hepatitis Hep C Support** 186 King St, London. For those infected as well as affected by Hep C. Contact: 519-434-1601, 1-866-920-1601

www.hivaidsconnection.com

Niagara Health System – Hepatitis C Care Clinic (HCCC) Clinics:

New Port Centre-Port Colborne, 4 Adams Street - St Catharines, Niagara Falls Hospital. Education, counseling, individual/group support, treatment, outreach, and harm reduction. Contact 905-378-4647 ext 32554 and HCCC@niagarahealth.on.ca/www.niagarahealth.on.ca/services/hepatitis-e-care

Oshawa Community Health Centre Hepatitis C Team Drop-in, lunch provided each Thurs. 12-1 PM, 79 McMillan St. www.ochc.ca Contact 1-855-808-6242

Owen Sound Info, support. Contact Debby Minielly *dminiel*-

<u>ly@publichealthgreybruce.on.ca</u> 1-800-263-3456 Ext. 1257, 519-376-9420 Ext. 1257,

www.publichealthgreybruce.on.ca

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Peel Region (Brampton, Mississauga, Caledon) 905-799-7700 healthlinepeel@peelregion.ca

**St. Catharines** Contact Joe 905-682-6194

**Toronto CLF** 1<sup>st</sup> Mon. monthly Oct.—June, 7:30 PM, North York Civic Centre, 5100 Yonge Street. Contact Billie 416-491-3353, ext. 4932.

<u>bpotkonjak@liver.ca</u> www.liver.ca

**Thunder Bay** Hep C support. Contact Sarah Tycholiz 807-345-1516 (or for 807 area only 1-800-488-5840)

Unified Networkers of Drug Users Nationally undun@sympatico.ca

York Region Hepatitis C Education Group 3<sup>rd</sup> Wed. monthly, 7:30 PM, York Region Health Services, 4261 Hwy 7 East, B6-9, Unionville. Contact 905-940-1333, 1-800-361-5653 info@hepcyorkregion.org www.hepcyorkregion.org

#### **OUEBEC:**

Quebec City Region Contact Renée Daurio 418-836-2307 reneedaurio@hotmail.com

CAPAHC support group meetings 3<sup>rd</sup> Thurs. monthly 6-8PM, 5055 Rivard St., Montreal) Contact 514-521-0444 or 1-866-522-0444

#### ATLANTIC PROVINCES

Hepatitis Outreach Society of NS. Info and support line for the entire province. Call 1-800-521-0572, 902-420-1767 Online Peer Support: <a href="mailto:info@hepns.ca">info@hepns.ca</a> <a href="https://www.hepns.ca">www.hepns.ca</a> <a href="https://www.hepns.ca">www.hepns.ca</a>

#### PRAIRIE PROVINCES:

Manitoba Hepatitis C phone and email support and outreach. Contact Kirk at info@mbhepc.org.
Direct line: 1-204-231-1437

Manitoba CLF each Thu 1:30-3. 375 York Avenue, Suite 210, Winnipeg, Contact Bianca 204-831-6231 bpengelly@liver.ca

Medicine Hat, AB Hep C Support Group 1st & 3rd Wed. monthly, 6:30 PM, HIV/ AIDS Network of S.E AB Assoc, 550 Allowance Ave. Contact 403-527-7099 bettyc2@hivnetwork.ca

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